

## Ben

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHO LOST A CHILD TO  
MEDIUM CHAIN ACYL-COA DEHYDROGENASE DEFICIENCY (MCAD).

On February 19, 1998, Ben entered our life. He was a beautiful full term baby boy and our third child. Ben received the minimum state-mandated newborn screenings after he was born and was thought to be healthy.

During routine well-baby check-ups, Ben was thought to be a typical child. He was growing and developing normally.



During his brief 2 ½ years of life, Ben had learned to swim, to identify landmarks on the way to his grandparents' house, to distinguish among the vehicles his various grandparents drove, to drive his own little Power Wheels Ford Pick-Up Truck, to pick out his Daddy's backhoe key among a cluster of other keys, and had become fully potty-trained.

He seemed so normal, so healthy. Little did our family realize that a "silent killer" was present in our Ben.

On Monday, August 7, 2000, Ben became ill with vomiting. He had no other symptoms such as fever or diarrhea. He had been sick with vomiting before, so, we treated him by forcing fluids and small amounts of food to prevent dehydration. Vince and I stayed up with Ben until 10:30 while continuing to give him drinks. He slept on a pallet beside our bed that night. At 1:30 A.M. the next morning, I awoke to find Ben opening and closing his eyes, but unresponsive to our commands. Suddenly, Ben stopped breathing and his heart stopped beating. I began CPR immediately on our living room floor while whispering what I feared might be my last words to my son. Vince was on the phone searching for advice and help from 911 while asking Ben to come back. Ben didn't come back. He was transported to the local hospital by helicopter where attempts were made to revive him. No one was successful. Our apparently healthy son was dead within 12 hours of showing symptoms of illness.

Doctors and state health officials speculated about the cause of Ben's death for almost a month. The list of misdiagnosis included: sepsis, meningitis, mosquito-borne encephalitis, and Reye's Syndrome. About a month after Ben's autopsy, we learned the real cause of death, a disorder we had never heard of before, MCAD.

Adding to our devastation, about a week after Ben's MCAD diagnosis, we learned that his disorder could have

been detected at birth or any other time before his fatal crisis with a \$25 blood test. With this simple, inexpensive screening, doctors would have been able to diagnose Ben's "silent" disorder. With an early diagnosis, a treatment plan would have been devised and Ben's prognosis for a normal, healthy life would have been excellent. One doctor told us that with early detection of the MCAD disorder that Ben would most surely be alive.

Since Ben's death, we have been very busy promoting expanded newborn screenings. We have written local pediatricians and obstetricians/gynecologists several times. We have written our legislators. Two local state representatives wrote a bill to require that doctors at least inform parents of these additional tests that are not required by law so that parents will have a choice to test their children, a choice we never had. The bill was titled, "Ben's Bill". It was signed by the governor into law during a special ceremonial signing on Monday, April 16, 2001.

Although our lives will never be the same because losing Ben was so unnecessary and unacceptable, we are proud of Ben's impact on the future of children's health in our state. We will continue our efforts to mandate CNBS in our state so that our children will have the best chance for a healthy life and parents will not have to endure such immense pain.

Written September 2001 by Vince and Robin Haygood

robin@savebabies.org

Parents of:

Ben, MCAD-postmortem diagnosis (2/19/98 - 8/8/2000)

Lori, unaffected

Leslie, unaffected

Bo, unaffected

Belden, Mississippi